

Pre Budget Submission 2018

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ASTHMA IN IRELAND

- √ 470,000 people in Ireland have asthma
- ✓ Ireland has the fourth highest prevalence of asthma in the world
- √ 60% of people in Ireland have uncontrolled asthma, meaning they are at risk of an asthma attack
- ✓ Approximately 1 person dies every week in Ireland from asthma
- ✓ Every 26 minutes someone visits the Emergency
 Department because of asthma
- √ 90% of asthma deaths are preventable
- ✓ 1 in every 10 adults has asthma
- √ 1 in every 5 children has asthma
- ✓ Adults miss an average of
 12 days at work each year
 due to asthma
- ✓ Children miss an average of 10 days at school each year due to asthma
- ✓ The economic burden of asthma in Ireland is estimated at €500m per year

Executive Summary

The Asthma Society's mission is to save and improve the lives of people with asthma.

While asthma cannot be cured, it can be controlled.

However, issues such as the high cost of preventative medication, inadequate primary care services and poor air quality mean that 60% of Irish asthmatics don't have their asthma under control.

As a result, someone ends up in ED every 26 minutes and fifty people die every year from the condition.

Implementing the recommendations in this paper would change this and dramatically improve the lives of the 470,000 Irish people with asthma and their families.

We are calling for the government to:

- 1. Reduce the cost of asthma medication;
- 2. Improve primary care for people with asthma:
- 3. Equip schools and sports clubs to support children with asthma;
- 4. Provide specialised secondary care for children;
- 5. Improve outdoor air quality;
- 6. Improve indoor air quality;
- 7. Reduce the threat from tobacco; and
- 8. Fund the Asthma Society's Vital Work.

STOP ASTHMA DEATHS

Asthma - A Manageable Condition That Takes Far Too Many Lives In Ireland

While asthma cannot be cured, it can be controlled. With proper care and medication most asthmatics can live full lives, symptom free. Having asthma certainly hasn't stopped David Beckham, Ronan O'Gara, John O'Shea or Seamus Callinan from achieving their full potential.

However, 60% of Irish asthmatics do not have their condition under control. As a result, they are at risk of having a serious attack at any time.

Every 26 minutes someone ends up in a hospital emergency department with a life threatening attack, a total of 20,000 ED visits every year. Asthma also accounts for 50,000 visits per annum to GP out of hours services.

In Ireland, one person a week dies from an asthma attack. Tragically, 90% of these deaths are preventable.

Asthma-related Deaths - What Bereaved Families Say:

The Asthma Society has been contacted by several families who lost loved ones to asthma attacks in 2015 and 2016. One boy was seven years old. One was sixteen. One was nineteen. Two were twenty-one.

These families have told us they had no idea asthma could kill. They have urged us to do more to make people aware of this and highlight the importance of taking preventative medication every single day even if you are feeling well.

Michael Martin has just recorded a TV ad for the Asthma Society about his son Chris who died from an asthma attack on Stephens Day 2015. Michael was suffering from cancer at the time and was on his way to Knock to pray for his illness to be cured. He got a phone call from home telling him Chris was having a bad asthma attack. Michael rushed home to Wexford but it was too late. Chris died before he got there. Chris was a fit and healthy young man and played rugby for UCC. He had asthma since he was a kid and used his reliever inhaler while playing sports. However, Michael says he would often forget to take his preventative medication. Neither Michael or Chris had any idea that doing so could cost him his life. Michael is working with the Asthma Society to raise awareness about asthma deaths because he doesn't want any other family to go through the trauma of losing a child to asthma.

Dylan McLoughlin was just sixteen years old when he died in February 2016. He was a fit and active boy, out mountain biking with his friends during the mid-term break, when he tragically suffered a fatal asthma attack. Dylan lived in Naas, Co. Kildare, Ireland, with his

Mum and Dad, Joan and Tom, his younger brothers Fionn and Glen, and beloved dog Drisco. He loved cycling, surfing and playing rugby for his local club in Naas.

Tipperary man Aaron Ryan died last summer when he had a fatal asthma attack while swimming with friends. He was just 21 years old. His partner was pregnant at the time and gave birth to their baby a few months later on Christmas Day.

Another mother wrote to us about her son:

"My reason for writing to you is that our beautiful 21 year old son died suddenly from an asthma attack on 21st July 2015. He was our only child and we are devastated....We had thousands at the funeral and afterwards. Not one person could believe you could die from asthma.....I am writing to you to ask you to please highlight this more. It is very very important to put the message out there and inform people – even parents of children with asthma don't know how serious it can be. We unfortunately are one of the unlucky ones. We lost our son and will never get over it. He was our only son and we lost him in 3 minutes." Her son had just qualified as a fitness instructor.

There is a popular misconception that only those with severe asthma are at risk of a serious attack or death. This is not the case. In fact, a 2014 study of asthma deaths in the UK found the majority of those who died had mild or moderate asthma. Unfortunately, many people with mild or moderate asthma underestimate their condition. They don't realise how serious asthma can be and don't appreciate the importance of taking preventative medication every single day even when they are feeling well. As outlined later in this paper, others know they should take a preventer inhaler every day but can't afford it because asthma is not included in the Long Term Illness Scheme.

90% of asthma deaths are preventable with proper treatment and care.

Please help us save and improve the lives of people with asthma by fighting for the recommendations in this paper to be implemented.

OUR BUDGET PRIORITIES

1. Reduce The Cost of Asthma Medication

A key part of good asthma control is taking preventative medication every day, even when you are well. Yet preventative asthma medication is very expensive in Ireland and can cost over €65 per month. As a result 40% of our members do not take their medication as prescribed. Many forgo taking preventative medication and rely instead on taking cheaper reliever inhalers when they have an attack. This is an extremely dangerous practice as reliever inhalers are often insufficient to combat severe asthma attacks. Not taking their preventative asthma medicine as prescribed leaves people at risk of a serious asthma attack, hospitalisation and death.

In 2015 Ireland had the highest rate of respiratory hospital admissions in 32 OECD countries.¹ Asthma is responsible for over 20,000 ED visits every year and over 50,000 visits to GP out of hour's services. Therefore, inadequate asthma control not only has a major negative impact on the individual, it also has a huge cost to the State. In fact, the economic burden of asthma in Ireland has been estimated at €533 million per annum, including health sector costs, premature deaths and reduced productivity due to illness.

While people with other chronic illnesses such as diabetes and epilepsy are entitled to free medication through the Long-term Illness Scheme, those with asthma are not. The Asthma Society is calling on the Government to change this by including people with asthma in the Long Term Illness Scheme or another targeted scheme such as a chronic disease card.

Recommendation:

1.1 Ensure the high cost of preventative medication is not a barrier to effective asthma control by including people with asthma in the Long Term Illness Scheme or another targeted scheme such as a chronic disease card.

2. Improve Primary Care For People With Asthma

Effective primary care is an essential component of asthma control. By ensuring that people are on the correct medication and educating them about how to manage their asthma, GPs, nurses and pharmacists can help to dramatically improve the quality of life of their patients. They can also reduce the huge burden on our secondary health system of avoidable hospital admissions.

Unfortunately, Ireland's current standard of primary care for people with asthma is far behind international best practice. A survey of our members found that 59% had not had their asthma reviewed in the previous year while 72% did not have a written asthma action plan.

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¹ The OECD 'Health at a Glance' survey 2015

The importance of improving primary care for people with asthma is recognised in Ireland's 'National Clinical Programme for Asthma' (NCPA), published in 2011. Under the NCPA everyone diagnosed with asthma was to be enrolled in a structured programme of free regular GP reviews, with a focus on patient education, empowerment and self-management. Patients would be educated on issues such as how to use their inhalers properly, the importance of taking preventative medication, and how to avoid their personal triggers. The programme was to be rolled out on a phased basis, starting with people with asthma who had attended a hospital emergency department in the previous year.

Similar initiatives in Finland and Australia dramatically improved health outcomes for people with asthma.

Due to the economic crisis, the NCPA was not implemented as planned.

The Asthma Society welcomes the emphasis on effective asthma control in the contract for the provision of free GP care to all children under the age of six. However, older children and adults, particularly those with severe asthma, must not be forgotten.

We are therefore calling on the Government to deliver on the commitment in the NCPA to a free structured asthma management programme for everyone with asthma. This could be delivered on a phased basis, starting with those with severe asthma.

The Government should also deliver on the commitment made in its 'Partnership Programme' to a new GP contract with an emphasis on enhanced primary care for people with chronic conditions such as asthma and eighty new primary care centres.

Given the danger flu can pose to people with asthma, we also recommend that an automatic notification system be put in place to advise asthmatics of the importance of getting the flu vaccine.

Recommendations:

- **2.1** Deliver on the commitment in the 'National Clinical Programme for Asthma' to a free structured asthma management programme for everyone with asthma.
- **2.2** As per the current Programme for Government, increase GP capacity to cater for chronic diseases like asthma and COPD by agreeing a new GP contract.
- **2.4** Deliver on the Programme for Government commitment to 80 new primary care centres to improve access to primary care and ultimately aid asthma management.
- **2.5** Put an automatic notification system in place to advise people with asthma of the importance of getting the flu vaccine.

3. Ensure Schools, Sports Clubs and Other Organisations Are Well-Equipped To Support Children With Asthma

As 1 in 5 Irish children have asthma, it is inevitable that at some point every school will have to deal with a student having an asthma attack. The same is the case for child and adult members of sports clubs and other organisations. It is therefore imperative that staff and volunteers in these settings know how to assist someone having an asthma attack.

In an emergency, having immediate access to a reliever inhaler could be the difference between life and death. However, sometimes an asthmatic may not have their own inhaler with them. To cater for such eventualities, all schools, colleges, sports clubs, gyms and other appropriate organisations should be encouraged to keep a spare reliever inhaler on site.

In October 2015, the Minister for Health signed new regulations allowing trained members of the public to administer life-saving rescue medicines such as epi pens, glucagon for diabetic hypoglycaemia and reliever asthma inhalers in emergency situations.².

While we welcome the intention behind these regulations, they are not working in practice because the conditions attached are overly onerous. For example, the regulations state that the person administering the inhaler must have been issued with a certificate stating that they have completed a course of training within the previous two years. This is simply not practical.

We accept such conditions may be appropriate for other emergency medication such as epi pens. However, they are wholly unnecessary for reliever inhalers. The risks of not giving someone an inhaler immediately far outweigh the risk of potential side effects such as dizziness which are minor and temporary. Up to 8 puffs of a reliever inhaler can be taken in one day.

The Asthma Society would be happy to work with the Department of Health, the education partners and other bodies to devise workable arrangements for the administration of reliever inhalers in emergency situations. We could also produce instructional posters and videos on how to use the devices correctly for dissemination to schools, clubs and other relevant organisations.

Recommendations:

3.1 The current ministerial regulations for the administration of salbutamol in emergency situations should be replaced with workable arrangements.

² S.I. No. 449/2015 - Medicinal Products (Prescription and Control of Supply) (Amendment) (No. 2) Regulations 2015.

3.2 The Department of Health should support the Asthma Society to develop instructional videos and posters for schools, sports clubs and other organisations on the administration of salbutamol in emergency situations.

4. Provide Specialised Secondary Care For Children

Ireland has the lowest number of respiratory consultants in Europe after Macedonia at 1.3 per 100,000 people, while the mean for Europe is 4.4.

We also have a shortage of pediatric respiratory consultants. As a result, children are waiting up to six months on average to see a respiratory consultant after a GP referral. Many parents have been forced to go private to avoid these long waiting periods.³ Others cannot afford to do so and so are left with the worry that their child will have a serious asthma attack while waiting to see a respiratory specialist.

Asthma nurses also have a critical role to play in helping to manage asthma. However, there are no paediatric asthma nurses in any of the regional centres (Cork, Galway or Limerick).

There are also no dedicated paediatric lung function labs with paediatric-trained lung function physiologists outside the Dublin children's hospitals. As a result, consultants in other hospitals have to try to assess children using adult equipment. This is even the case with children who have severe poorly controlled asthma.

Recommendations:

- **4.1** Additional paediatric consultants should be recruited to reduce waiting times for children
- **4.2** Each children's hospital and regional centre should have specialised asthma paediatric nurses.
- **4.3** Paediatric lung function labs should be put in place in Cork, Limerick and Galway regional hospitals, with trained paediatric physiologists.

5. Improve Outdoor Air Quality

Air quality was recently described by the World Health Organization (WHO) as the world's largest single environmental health risk, and Ireland is no different. The European Environmental Agency estimates that 1,229 lives are lost prematurely in Ireland because of poor air quality in a single year.

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³ A survey of Asthma Society members found that 23% of parents decided to go private to avoid these long waiting periods and therefore had to pay unnecessary expenses to get treatment for their children.

Pollution from motor vehicles, industrial plants, domestic solid fuels and other sources is bad for everyone's health but it has a massive impact on people with asthma. Air pollution is absorbed into the sinus, the airways and the lungs, triggering asthma symptoms.

In a survey of our members, 78% of them said that air pollution in their area affected their asthma. Some adults are unable to go outdoors during winter months because of the pollution created by domestic solid fuel burning particularly coal. Parents also stop their asthmatic children playing outside for the same reason.

While Ireland is largely within the EU limits for air pollution, it fairs poorly when measured against the World Health Organisation guidelines for emissions.

The Asthma Society welcomes the Government's commitment to a national ban on smoky coal and would like to see this implemented as soon as possible. However, we are concerned about emerging research which shows that solid fuels like wood and peat are also high in PM2.5 omissions. We also believe the Government should end the favourable tax treatment of motor diesel in light of research which shows that on short journeys the emissions from diesel cars are just as high as those from petrol cars.

We are also concerned about the lack of effective air quality monitoring in Ireland. At present, only 13 out of the 26 counties have air monitoring sites and those counties with sites have very limited capabilities. We only have 3 air monitoring sites in Ireland that can detect particulate matter in real-time. Others just provide historical data approximately every two months. Northern Ireland, by contrast, has 20 air monitoring sites gathering data and informing the public in real-time.

Asthmatics in Northern Ireland and across the UK can access real-time data and use it to avoid going outside during periods of particularly harmful emissions. Real-time air monitoring can also be used by public authorities to identify harmful emissions immediately and take steps to reduce future pollution. Wexford County Council introduced their own real-time air quality monitors in their five main towns, as well as a text alert for people with respiratory conditions when readings are high. The initiative is the first in Ireland and we hope further County Councils take similar action.

The Government should ensure every county has at least one real-time air monitoring station and that each of our five cities has at least three such facilities. The data from these stations should then be used to help deliver a proper national air quality monitoring and improvement programme.

We welcome the recent publication of two public consultation papers from the Department of the Environment and the EPA on a Clean Air Strategy for Ireland and on ambient air monitoring respectively. These papers acknowledge many of the issues raised above. It is imperative concrete plans and ringfenced funding are put in place as soon as possible to address these issues.

Recommendations:

5.1 The Government should proceed with an early implementation date for its nationwide ban on the selling and burning of smoking coal. It should also investigate the health consequences of burning wood and peat.

- **5.2** The favourable tax treatment of motor diesel should be reconsidered in light of research which shows that on short journeys the emissions from diesel cars are just as high as those from petrol cars.
- 5.3 A nationwide network of real-time air quality monitoring stations should be put in place as part of a pro-active plan to monitor and reduce harmful emissions. Each county should have at least one such station and each city should have at least three.

6. Improve Indoor Air Quality

Where we live affects our health. This is especially true for people with asthma.

Housing is identified in the Government's 'Healthy Ireland Framework' as being one of fourteen key areas that contribute to people's health and wellbeing.

Some indoor asthma triggers – such as dust, aerosol emissions and animal fur – can be managed relatively easily. However, others – such as poor insulation, inadequate ventilation, serious mould, inappropriate heating systems and the use of carpet rather than wood/laminate floors – are expensive to remedy. As a result, many low-income people with asthma are living in home environments which are seriously damaging to their health.

We welcome the 2016 Warmth and Wellbeing Pilot Scheme for people over 55 with asthma or COPD and for children under 12 with asthma in the Dublin 8, 10, 12, 22, and 24 areas living in households in receipt of the fuel allowance. The grant covers the full cost of having a new energy and/or heating system installed. The Better Energy Warmer Homes Scheme also funds home energy improvements for certain categories of social welfare recipients.

The Government should build on these initiatives by funding the cost of essential home improvements for all low-income households (not just those on social welfare) where at least one person has asthma or COPD. Given the number of low income families living in private rented accommodation, this sector should also be included. The programme could be rolled out on a phased basis, starting with families of children with asthma.

Recommendation:

6.1 Build on the success of the Warmth and Wellbeing Pilot Scheme and Better Energy Warmer Homes Scheme by providing funding for essential home improvements to all low-income families where at least one person has asthma or COPD. This could be done on a phased basis, starting with families of children with asthma.

7. Reduce The Threat From Tobacco

Tobacco smoke is one of the most common and dangerous triggers of asthma symptoms.

Smoking with asthma decreases lung function, reduces the effectiveness of medication, and increases the risk of virus and infection. Yet almost a quarter of asthmatics smoke. The 'Tobacco Free Ireland' report launched by Minister James Reilly in 2013 recommended targeted measures to help people with respiratory disorders to quit smoking. We urge the Government to implement this recommendation and to proceed with its plans for plain packaging and other measures designed to reduce smoking levels.

Steps should also be taken to reduce passive smoking.

Being subjected to passive smoking increases a person's likelihood of developing asthma. For example, babies born to mothers who smoke while pregnant are more likely to develop asthma, as are children exposed to tobacco smoke in the home. Passive smoking is also a common trigger of asthma symptoms and can lead to serious attacks.

The workplace smoking ban was a major step forward, as was the decision of the last government to ban smoking in cars with children. Most local authorities have also banned smoking in playgrounds. However, asthmatics are still exposed to secondhand smoke in other public places, including in parks, on beaches, at bus stops, on the sidelines of sports pitches, and immediately outside the exits of shops and other buildings. Smoking at such locations is banned in many parts of the United States and should also be banned here.

The Asthma Society recognises that e-cigarettes can help people to quit tobacco smoking. However, we share the World Health Organisation's concern that vaping may undermine the success of anti-tobacco initiatives by re-normalising smoking and acting as a gateway to smoking for young people. We are also concerned about the potential health impacts of passive vaping. We therefore believe the advertising, sale and use of e-cigarettes should be regulated in the same way as tobacco and that the workplace smoking ban should be extended to e-cigarettes. This would not in any way hinder the use of e-cigarettes to quit smoking. It would simply ensure that they are subjected to sensible regulation as called for by the World Health Organisation.

Recommendations:

- **7.1** Continue to deliver targeted measures to help people with respiratory disorders to quit smoking as recommended in the 'Tobacco Free Ireland' report.
- **7.2** Proceed with plans for plain packaging and other measures designed to reduce smoking levels.
- **7.3** Extend the smoking ban to other public places such as parks, beaches, bus stops, the sidelines of sportspitches, and immediately outside the exits of shops and other buildings.
- **7.4** Ban the use of e-cigarettes in restaurants, bars and cafes and regulate their advertising, sale and use in the same way as cigarettes.

8. Fund The Asthma Society's Vital Work

The Asthma Society is the only national representative body for the 470,000 Irish people with asthma.

We help save and improve the lives of people with asthma by:

- Providing services such as our free adviceline, pharmacy clinics and training for healthcare professionals;
- Providing information for patients about asthma management on our website, social media channels and in printed booklets;
- Lobbying the Government to improve services for people with asthma and participating in the working group for the HSE's National Clinical Programme for Asthma; and
- Supporting research into the causes and treatment of asthma.

However, our ability to do this work has been hampered by the loss of Government funding, particularly the Charitable Lotteries Fund.

The Society received significant funding from this scheme from 1997 on. In 2012 the Government announced its intention to phase out the fund over the following three years, with reduced payments each year until it was closed completely. We received €371,277 from the Charitable Lotteries Fund in 2012, €240,229 in 2013, €108,968 in 2014 and €51,742 in 2015. In 2016, we received no funding from this source.

While we have had some success in attracting funding from other sources, including other statutory schemes, we have been unable to compensate for losing such a large amount of income. As a result, we have been left with a significant shortfall and are unable to do as much patient and stakeholder education work in particular as we would like.

For example, we have developed excellent educational materials for schools and sports clubs but we don't have the resources to distribute them. These materials could save lives. We are also unable to accommodate all the requests we receive for nurse talks from schools and other groups.

Government funding for the Asthma Society's patient education work would enable us to help more people manage their asthma better, reducing their reliance on the health service and their risk of hospitalisation. This would in turn save the State money and reduce pressure on hospital emergency departments.

Hospital Visits and Admissions for People with Asthma (2014)

County	Population	People with Asthma	Hospital Visits	Hospital Admissions	
Carlow	54,612	5,355	298	74	
Cavan	73,183	7,266	399	99	
Clare	117,196	11,433	639	159	
Cork	519,032	50,130 2,828		703	
Donegal	161,137	15,894 878		218	
Dublin	1,272,469	120,668	6,937	1,724	
Galway	250,653	24,190	1,366	339	
Kerry	145,505	13,795	793	197	
Kildare	210,312	21,193	1,146	285	
Kilkenny	95,419	9,312	520	129	
Laois	80,559	8,119	439	109	
Leitrim	31,798	3,062	173	43	
Limerick	191,809	18,443	1,045	260	
Longford	39,000	3,851	212	53	
Louth	122,897	12,207	670	166	
Мауо	130,638	12,509	712	177	
Meath	184,135	18,654	1,003	249	
Monaghan	60,483	5,923	330	82	
Offaly	76,687	7,611	418	104	
Roscommon	64,065	6,154	349	87	
Sligo	65,393	6,235	356	89	
Tipperary	158,754	15,377	865	215	
Waterford	113,795	11,039	620	154	
Westmeath	86,164	8,483	469	117	
Wexford	145,320	14,268	792 197		
Wicklow	136,640	13,446	745 187		

School Going Children with Asthma Statistics 2013/2014

County	Primary Schools		Secondary Schools		All School going children	
	Total	Asthma	Total	Asthma	Total	Asthma
Carlow	7,371	1,474	5,855	1,171	13,226	2,645
Cavan	9,454	1,891	6,251	1,250	15,705	3,141
Clare	13,830	2,766	8,016	1,603	21,846	4,369
Cork City	13,992	2,798	14,958	2,992	28,950	5,790
Cork County	46,303	9,261	28,895	5,779	75,198	15,040
Donegal	19,073	3,815	12,731	2,546	31,804	6,361
Dublin City	45,247	9,049	38,235	7,647	83,482	16,696
Dun Laogh/ Rath	18,490	3,698	17,388	3,478	35,878	7,176
Fingal	35,072	7,014	18,836	3,767	53,908	10,782
Galway City	7,516	1,503	6,580	1,316	14,096	2,819
Galway County	21,708	4,342	12,738	2,548	34,446	6,889
Kerry	15,922	3,184	11,130	2,226	27,052	5,410
Kildare	28,869	5,774	16,840	3,368	45,709	9,142
Kilkenny	10,896	2,179	7,460	1,492	18,356	3,671
Laois	10,782	2,156	5,319	1,064	16,101	3,220
Leitrim	3,628	726	2,513	503	6,141	1,228
Limerick City	7,159	1,432	8,287	1,657	15,446	3,089
Limerick County	14,898	2,980	8,283	1,657	23,181	4,636
Longford	5,233	1,047	3,723	745	8,956	1,791
Louth	16,671	3,334	12,162	2,432	28,833	5,767
Mayo	14,479	2,896	10,657	2,131	25,136	5,027
Meath	25,474	5,095	13,258	2,652	38,732	7,746
Monaghan	7,312	1,462	5,817	1,163	13,129	2,626
Offaly	9,758	1,952	5,869	1,174	15,627	3,125
Roscommon	7,121	1,424	3,211	642	10,332	2,066
Sligo	7,188	1,438	5,487	1,097	12,675	2,535
South Dublin	33,733	6,747	21,416	4,283	55,149	11,030
Tipperary	18,573	3,715	13,973	2,795	32,546	6,509
Waterford City	6,293	1,259	5,234	1,047	11,527	2,305
Waterford County	7,911	1,582	4,215	843	12,126	2,425
Westmeath	10,935	2,187	8,629	1,726	19,564	3,913
Wexford	18,419	3,684	12,051	2,410	30,470	6,094
Wicklow	17,007	3,401	11,161	2,232	28,168	5,634
TOTAL	536,317	107,263	367,178	73,436	903,495	180,699

For further information on the issues raised in this paper or services provided by the Asthma Society of Ireland, please contact Kevin Kelly (Advocacy and Communications Manager)

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